Quality of life and well-being of carers of people with dementia: are there differences between working and nonworking carers? Results from the IDEAL program

Article (Accepted Version)

Quality of life and wellbeing of carers of people with dementia: Are there differences between working and non-working carers? Results from the IDEAL Programme

Clarke R[1], Farina, N[2], Chen HL[1] and Rusted JM[3]*, in collaboration with the IDEAL programme team

[1]School of Education and Social Work, University of Sussex, Brighton, UK: rc362@sussex.ac.uk; h.l. chen@sussex.ac.uk

[2]Centre for Dementia Studies, Brighton and Sussex Medical School, Brighton, UK: n.farina@bsms.ac.uk

[3]School of Psychology, University of Sussex, Brighton, UK:

*Corresponding author –
Jennifer Rusted
School of Psychology
Sussex University
BN1 9QH

+44 1273 678325

j.rusted@sussex.ac.uk

This study was approved by the Sussex University review board (reference: 16/EM/0383). The IDEAL Study was approved by the Wales Research Ethics Committee 5 (reference 13/WA/0405), the Scotland A Research Ethics Committee (reference 14/SS/0010) and the Ethics Committee of the School of Psychology, Bangor University (reference 2014 – 11684). The IDEAL Study is registered with UKCRN, registration number 16593.

Funding:

The work was completed as part of a PhD scholarship awarded to the first author funded by the Economic and Social Research Council (UK) and the National Institute for Health Research (UK) through grant ES/L001853/2 'Improving the experience of dementia and enhancing active life: living well with dementia' (Investigators: L. Clare, I.R. Jones, C.Victor, J.V. Hindle, R.W.Jones, M.Knapp, M.Kopelman, R.Litherland, A.Martyr, F.Matthews, R.G.Morris, S.M.Nelis, J.Pickett, C.Quinn, J.Rusted, J.Thom). RC studentship (reference ES/L001853/1); studentship: ES/L001853/1). The IDEAL (Improving the experience of Dementia and Enhancing Active Life) Programme was originally a 5-year UK national longitudinal study with 3 time-points; The IDEAL-2 study - 'Improving the experience of Dementia and Enhancing Active Life: a longitudinal perspective on living well with dementia' is funded by the Alzheimer's Society [grant number 348 (AS-PR2-16-001)], provides support for three further waves of assessment of the IDEAL cohort (Time 4 – Time 6) (see :http://www.idealproject.org.uk/about/). The funders had no role in the study design, data collection, data analysis and interpretation, writing of the report, or the decision to submit the article for publication.

Acknowledgements:

The support of all participants, and funding from ESRC, NIHR, and Alzheimer's Society is gratefully acknowledged.

Author contributions:

RC: research design; data analysis, interpretation, initial draft of the report. NF: data analysis, interpretation and writing, and final approval of all data analyses. HLC: research design; interpretation and writing. JR: research design; data analysis, interpretation and final draft.

Conflict of interests:

We have no conflict of interest to declare.

ABSTRACT

Objectives: To identify differences in quality of life and wellbeing between working and non-working dementia carers and the relative contribution of psychological characteristics, care-giving experience and social support.

Methods: Multiple regressions modelled the contribution of working status, caregiver experiences, psychological and social resources to carer QoL (EQ-5D) and wellbeing (WHO-5).

Results: After controlling for age, gender, carer-dyad relationship, severity of dementia, working status contributed significant variance to EQ-5D (2%) but not to WHO-5 scores. Independent of working status, higher self-esteem and reduced stress contributed to variance in both models. Self-efficacy, social support and positive perceptions of caregiving additionally contributed to higher WHO-5 scores.

Conclusion: Working status associated with higher EQ-5D QoL; this may reflect the sustained sense of independence associated with supported work opportunities for carers. Outside of working status, the findings support the importance of psychological and social factors as targets to improved mental health for dementia carers.

Keywords: dementia; caregiver; employment; well-being; quality of life

Introduction

Family and friends act as primary caregivers for an estimated 50 million people with dementia (PwD) worldwide, with nearly 10 million new carers every year (WHO, 2017). An estimated 60% in US and 18% in the UK are working carers, reflecting increasing female employment, social-security reform and other institutional changes (e.g. to state/work pensions) precipitated by increasing life expectancy (AARP, 2015; NHS Digital, 2017).

In the UK alone, this amounts to an estimated 270,000 carers combining dementia care with a working role (Doewick & Southern, 2014). Work-family reconciliation is recognised as an independent right (Masselot & Caracciolo di Torella, 2010) and the Carers Strategy is embedded in the Government's general principle that paid work is vital for ensuring financial independence, preventing social exclusion, and enriching personal wellbeing (Hillage & Pollard, 1998).

For all family carers of PwD, providing care can be challenging (Brodaty & Donkin, 2009). Compared to family carers of people without dementia, dementia carers have reported providing more help with daily activities, higher levels of caregiving: social activity conflict, more interrupted sleep, higher depression and hopelessness (Moon & Dilworth-Anderson, 2015). Care-recipient behaviours, caregiving competence, quality of the carer-dyad relationship and amount of social support all impact carer's QoL (Brodaty & Donkin, 2009; LaFontaine & Oyebode, 2013; Rattinger et al., 2016; Joling et al., 2017; Quinn et al, 2019a), and this in turn impacts QoL of the care recipient (Quinn et al, 2019b).

The Stress Process model (SPM) (Pearlin, Mullan, Sample & Skaff, 1990) recognises that dependency level of the PwD, role captivity but also perceived work-care conflict represent key stressors predicting poorer wellbeing for dementia family carers. Positive coping strategies, (reappraisal, active problem-solving), can reduce their impact, lowering rates of depression (Papastavrou et al., 2011) and improving mental and physical health and life satisfaction (Braun et al, 2009). Indeed, employment has been associated with positive wellbeing outcomes for carers, providing increased financial resources, protective respite from care responsibilities (Healthways & Coughlin, 2010; Newbronner, Chamberlain, Borthwick, Baxter & Glenning, 2013), personal satisfaction through work-based achievements, and increased opportunities for social activities (Utz, Lund, Caserta & Wright, 2011). Nevertheless, this additional role adds to the demands of dementia care, and other studies have reported that carers balancing work with caregiving have increased depressive symptoms (Dugan et al., 2016) poorer emotional, physical and general health, and social functioning (Nurfatihah et al. 2013; Wang, Shyu, Tsai, Yang & Yao, 2013).

A recent systematic review reported that good physical and mental health, independence (i.e., time not spent caring), and opportunity for respite associated with better carer QoL (Farina et al, 2017). In carers of people with dementia recruited to a large UK study, psychological characteristics and psychological health were primary determinants of living well (the IDEAL programme) (Clare et al, 2014, 2019). Additionally, Lamont et al (2019) reported that, controlling for age, sex, and number of hours of caregiving, self-efficacy, optimism and self-esteem were independently associated with capability of carers of PwD to 'live well'. These recent papers all report analyses independent of working status.

Using data from a large cohort of working carers, here we identify the factors associated with sustainable QoL and wellbeing in family carers of PwD who are maintaining employment alongside the caring role. We ask:

1. Do QoL and wellbeing differ for working and non-working dementia carers (henceforth DWC and DNWC respectively)?

2. What is the relative contribution of psychological characteristics, care-giving experience and social support resources to QoL and wellbeing among DWC and DNWC?

Perceived overlap between the concepts of QoL and wellbeing have encouraged the common practice of interchangeable usage of these terms (Schalock, 2004; Diener, 2006; Camfield & Skevington, 2008). A secondary question is the extent to which these concepts do indeed overlap in modelling the relationships of interest here.

Research design and methods

Ethics

This study was approved by the local University review board (reference: 16/EM/0383). The IDEAL Study was approved by the Wales Research Ethics Committee 5 (reference 13/WA/0405), the Scotland A Research Ethics Committee (reference 14/SS/0010) and the Ethics Committee of the School of Psychology, Bangor University (reference 2014 – 11684). The IDEAL Study is registered with UKCRN, registration number 16593.

Sample

Participants were recruited through NHS memory services and other specialist clinics, and via the online UK Join Dementia Research portal www.joindementiaresearch.nihr.ac.uk/, between July 2014 and August 2016 and included 1283 primary family carers of people with dementia.

The majority were caring for persons diagnosed with Alzheimer's disease (N=715, 55.7%), with the remaining diagnoses including mixed (N=263), vascular (N=142), frontotemporal (N=45), Parkinson's disease (N=43), Lewy Body (N=43), unspecified, and 'other' dementia (N=5). We excluded the 45 carers who provide care for people with frontotemporal dementia, based on the pronounced behavioural differences in this diagnosis (Nicolaou, Egan Gasson & Kane, 2010). DWC were self-defined as in paid employment and/or voluntary (unpaid) work. DNWC were self-defined as retired, unable to work, or at home and not looking for work; 45 carers were excluded due to ambiguity in employment status, leaving 215 DWC and 973 DNWC. Mean age for DNWC was 72.3 years (range 31-96: 66.5% female; 89.6% spouses), and for DWC was 55.5 years (range 26-86; 79.1% female; 38.1% spouses). We first modelled the data from the full cohort. Recognising the large disparity in numbers and in age of the DWC vs DNWC, we then completed a parallel set of analyses on a subset of the cohort, matched for age by working status (essentially excluding all carers above the age of 65). This comprised 184 DWC (79.2% female; 27.7% spouses) and 178 DNWC (81.5% female; 60.7% spouses), age range 26-65 for both groups.

Instruments:

We used a subset of measures from the IDEAL Study Time 1 dataset, as follows:

Outcome measures: WHO-5 Wellbeing Index (Bech, 2004) charted wellbeing, covering positive mood (good spirits, relaxation), vitality (active, fresh, rested), and general interests (interested in things); positively worded, it avoids symptom-related language. EQ-5D-3L (EuroQoL Group, 1990), a standardised measure of health status, indexed QoL. It comprises five dimensions: mobility, self-care, usual activities, pain/discomfort, anxiety/depression.

Covariate measures: carer age, gender, carer-dyad relationship and care recipient dependence (Dependence Scale (Brickman et al., 2002)).

The following measures were included as independent variables in the models:

Psychological characteristics: Rosenberg Self-Esteem Scale (Rosenberg, 1965); and the Generalised Self-Efficacy Scale (Schwarzer & Jerusalem, 1995).

Caregiving experience: Role Captivity Scale (Pearlin et al., 1990); The Relative Stress Scale (Greene, Smith, Gardiner & Timbury, 1982); The Positive Aspects of Caregiving Scale (Tarlow et al., 2004); The Management of Situation Scale (Pearlin et al., 1990); The Caregiving Competence Scale (Robertson et al., 2007). The COPE Index (McKee et al., 2003: a single item global carer coping question - "Do you think you cope well as a carer?"); Modified Social Restriction Scale (Balducci et al., 2008).

Social support: Lubben Social Network Scale-6 (LSNS-6 Lubben et al., 2006); WHOQOL-BREF – Social relationships sub-scale (Skevington, Lofty & O'Connell, 2004).

Appendix 1 in Supplementary File provides more detailed information on these instruments.

Methodology

Preliminary analyses established the comparability of DWC and DNWC for outcome and covariate indices (categorical data: Pearson's Chi-Square; continuous data: two-tailed t-test).

A multivariate analysis of covariance (MANCOVA) used WHO-5 and EQ-5D as dependent variables, controlling for covariates (age, gender, carer-dyad relationship and dependence), to determine whether working status significantly predicted variance of the primary outcomes, and potential overlap between the two dependents.

Subsequently, multiple regression models identified the variance accounted for by working status on QoL (EQ-5D index) and well-being (WHO-5) outcomes independently. In the first block, confounding variables (age, gender, carer-dyad relationship, dependence) were entered as covariates. In the second block, working status was entered. Finally, all independent variables (Relative Stress Scale; Self-esteem; Management of Situation; Role Captivity; Positive Aspects of Caregiving; Caregiver Coping; Caregiving Competence; Social network; Social restriction; Social relationships) were entered step-wise, and variables that significantly contributed variance ($p<.05$) were retained in the model.

Multicollinearity was checked for all independent variables entered into the models, with threshold variance inflation factor (VIF) > 5 (Akinwande, Dikko & Samson, 2015). No variables exceeded threshold.

Results

Table 1 describes the two samples, stratified by working status.

In the full cohort, DNWC were significantly older than DWC ($t(1185) = -24.78$, $p < 0.001$), but did not differ on dependence level of care recipients ($t(1113) = 0.07$, $p > 0.05$). DWC reported better QoL (ie. higher EQ-5D index) compared to DNWC ($t(1160) = 6.32$, $p < 0.001$)); WHO-5 scores did not differ ($t(1152) = 0.88$, $p > 0.05$)). DWC reported significantly higher self-efficacy scores, while, DNWC reported significantly higher carer competence alongside higher social restriction scores.

[Insert Table 1 here]

In the age-matched sub-sample, DNWC were older than DWC, by 4 years ($t(360) = -7.94$, $p < 0.001$)), but did not differ in dependence level of care recipients ($t(339) = -1.40$, $p < 0.1$). DWC reported a significantly higher EQ-5D index ($t(359) = 5.29$, $p < 0.001$)), and higher WHO-5 scores ($t(351) = 2.12$, $p < 0.05$)). DWC reported significantly higher self-esteem, self-efficacy, and positive aspects of caring scores. DNWC reported significantly higher carer competence but higher relative stress, role captivity and social restriction scores.

Multivariate analysis of covariance (MANCOVA)

The initial MANCOVA for the full cohort revealed a statistically significant difference between DWC and DNWC on the combined variables (EQ-5D and WHO-5) after controlling for covariates $F(2,1073) = 9.79$, $p < .0001$, Wilks' $\Lambda = 0.98$, partial $\eta 2 = 0.02$. For the age-matched subsample, the picture was the same: a statistically significant difference between DWC and DNWC on the combined variables (EQ-5D and WHO-5) after controlling for covariates, $F(2, 331) = 9.99$, $p < 0.001$, Wilks' $\Lambda = 0.94$, partial $\eta 2 = 0.06$.

Multiple Regression Models

Distinctions emerged between the two outcome measures in the independent regression models.

Model A: EQ-5D (Table 2a, b; full models in Appendix 2 of Supplementary File)

Full Sample: For EQ-5D, Model A, working status accounted for 2% of the variance. DNWC associated with poorer EQ-5D scores ($\beta = -.17$, $p < 0.001$). Three additional variables

were retained following step-wise additions into the model (block 3): self-esteem, relative stress and role captivity. These three accounted for 12% of the variance in the final model, with higher self-esteem, reduced relative stress and greater role captivity associated with higher EQ-5D scores. The final model accounted for 18% variance and was significantly associated with EQ-5D scores ($F=28.43$, $p<0.0001$). Of the four covariates, only carer-dyad relationship contributed significantly to the final model.

Age-matched subsample: For EQ-5D, Model A, working status accounted for 5% of the variance. DNWC associated with poorer EQ-5D scores ($\beta=-.25$, $p<0.001$). Three additional variables were retained following step-wise additions into the model (block 3): self-esteem, relative stress and role captivity. These three accounted for 16% of the variance in the final model, with higher self-esteem, reduced relative stress, and greater role captivity associated with better EQ-5D scores. The final model accounted for 26% of variance and was significantly associated with EQ-5D scores ($F=14.38$, $p<0.0001$)

[Insert Table 2 here]

Model B: WHO-5 (Table 3a, b; full models in Appendix 3 of Supplementary File)

Full Sample: For WHO-5, Model B, working status accounted for 0% of the variance. DNWC associated with poorer QoL scores, but this was not statistically significant ($\beta=-.05$, $p=0.19$). Seven additional variables were retained following step-wise additions into the model (block 3): relative stress, self-esteem, social relationships, self-efficacy, social network, social restriction, and positive aspects of caregiving. These variables accounted for an additional 36% of the variance in the final model, which accounted for 47% of the variance, and significantly

predicted WHO-5 scores (F=74.36, p<0.001). Of the covariates, only gender contributed significantly to the final model; being male associated with a higher wellbeing.

Age-matched sample: Model B (WHO-5) remained largely unchanged compared to the full sample. Working status accounted for 1% of the variance in the second step of the model (β=-.13, p=0.04), but this association did not remain following the step-wise additions (block 3). Only relative stress, self-esteem, social relationships, and self-efficacy were retained in the step-wise model building. The final model accounted for (47%) of variance, similar to the full sample model.

[Insert Table 3 here]

Discussion

This paper explored potential differences in QoL and wellbeing for working and nonworking carers of PwD. It is the first study to report working carer data from the UK IDEAL programme, which provided a relatively large sample of working carers (N= 215), and a broad set of psychological, carer experience and social relationship measures to characterise non-working versus working carers. By modelling the data both from the whole sample and from a subset matched for age, we demonstrate the robustness of the findings to age-related heterogeneity.

Comparing QoL and wellbeing in DWC and DNWC

In this study, working status contributed positively to carer QoL, measured by EQ-5D, but did not contribute to wellbeing, indexed by WHO-5 scores. The models were essentially

comparable across the full and age-matched samples, though this may reflect the fact that the large majority of the working carers were under 65 years old and therefore included in both samples.

Higher levels of depression and diminished QoL are reported often in older family carers of people with dementia (Schölzel-Dorenbos, Draskovic, Vernooij-danssen & Olde-Rikkert, 2009; Fonareva & Oken, 2014), likely compounded by a negative association with time spent caring (Bruvik, Ulstein, Ranhoff & Engedal, 2012; blinded for review ♯1, 2017). While it is possible that DWC age (the majority being 26-65 years) contributed to the positive association with EQ-5D scores, it is important to note that age did not contribute significant variance to either the age-matched or the full sample models for either EQ-5D or WHO-5.

Better QoL in DWC was reported in previous research (Healthways & Coughlin, 2010; Newbronner et al., 2013) suggesting employment is protective against the responsibilities of care and caregiving stress. Indeed, qualitative studies (Johannessen et al., 2016: Anderson & White, 2018) identify resilience and adaptive coping strategies, personal fulfilment and supportive social network with work-care balance and sustained self-esteem. DNWC, in contrast, reported higher social restriction scores but higher carer competence, suggesting work-care balance may impacts perceived competencies.

Common contributors to QoL and wellbeing for DWC and DNWC

Independent of working status, higher self-esteem and reduced relative stress were two common contributors to both QoL and wellbeing among both samples of DWC and DNWC. This reinforces the findings from Brodaty & Donkin (2009) and Lamont et al (2019), reporting associations between self-esteem and indices of QoL and wellbeing, and associations between stress, QoL (Häusler et al., 2016) and broad domains of emotional, psychological and physical

wellbeing (Ervin, Pallant & Reid, 2015; Raivio, Laakkonen & Pitkala, 2015) reported in other dementia family carer studies.

Independent of working status, being male associated with better QoL and wellbeing in the full sample. For EQ-5D (QoL), however, the significant association disappeared after the addition of self-esteem, relative stress and role captivity in the third step. This suggests a small gender effect, potentially attributable to other underlying psychological factors. Sharma, Chakrabati and Grover (2016) reported greater role-strain in female carers of PwD, and better adaptation to the caregiving role by male carers (Braun et al., 2009), though not all studies have found gender differences (Russell, 2001; Prince, 2004; Baker & Robertson, 2008). Importantly, also, carer-dyad relationship was not a significant contributor to the final models.

Arguably, the particular psychological, caregiving experiences, and supportive social resources explored here provided a better overall model for the WHO-5 wellbeing outcome than for the EQ-5D QoL outcome measures. The full and age-matched models both explained 47% of the variance (vs 18% for EQ-5D), and in addition to the factors common to both models, self-efficacy, social support (i.e. social relationships, social network, social restriction indices) and positive perceptions of caregiving contributed significantly to the full sample wellbeing model, for both DWC and DNWC.

Self-efficacy is negatively correlated with depression for dementia family caregivers (Gilliam & Steffen, 2006; Cheng, 2017), and positively with carer QoL (Crellin, Orrell, McDermott, & Charlesworth, 2014; blinded for review ♯1, 2017). The significant association between social support and well-being scores suggests increased in/formal support could be an effective target for sustaining wellbeing in carers with low self-efficacy.

Positive aspects of caring, social network and social restriction were less stable elements of the wellbeing model, and associated positively with well-being only for the full (older) sample. This may simply reflect the additional power conferred by the increased

numbers in the full sample. Consistent with Pearlin et al. (1990) and Brodaty & Donkin (2009), carers who employed social support from friends and family, regardless of employment status, reported higher wellbeing. Positive appraisals of caregiving may mitigate caregiving stress (Tarlow et al., 2004), improving caregiver competence, and self-rated health (Belle et al., 2006; Cheng, 2017). The significance of these factors only for the full (older) sample, emphasises the particular importance of social support and positive coping skills for older carers.

The relationship between quality of life (QoL) and wellbeing

The finding that working status contributed 2% of the variance to EQ-5D scores but did not significantly predict higher WHO-5 scores was unexpected, and suggests that the two measures capture somewhat different underlying constructs. The concepts are often used interchangeably (Camfield and Skevington, 2008; Tyack & Camic, 2017). Conceptually, however, the unidimensional WHO-5 does not directly map onto the dimensions of the EQ-5D. At an item-level, moderate associations (>0.5) are reported only between anxiety/depression and relaxed, anxiety/depression and good spirits, self-care and energy, and usual activities and energy (Janssen et al., 2013). Skevington & Böhnke (2018) argue that integrating measures of subjective wellbeing and QoL would achieve a more holistic measure of subjective health than either measure alone. Other definitions consider QoL as a broader ranging concept, impacted by physical and psychological health, personal convictions, social relationships, and environment (WHO, 2018), and recent research provides a rationale for the inclusion of more domains currently unrepresented in generic QoL models such as EQ-5D (Daley et al., 2018).

The current findings argue for a reconsideration of the interchangeability of the EQ-5D health-related QoL and the WHO-5 wellbeing measures. As Camfield and Skevington (2008)

conclude, without definitional and conceptual agreement, it is not yet possible to determine what the universal relationship between QoL and subjective wellbeing really is.

Limitations of the study

This study has some limitations. First, the full sample had many more DNWC than DWC. This is unsurprising since many family carers give up work to provide full-time care (HM Government, 2014), and many were in the age group that retired from work before the statutory UK retirement age was lifted. Nevertheless, the factors most prominently influencing QoL and well-being were largely comparable across the full and the age-matched samples, while indicating some important additional sources of variance for the (full) older sample. In addition, carer-dyad relationship contributed variance in the first-level models, and it is possible that the uneven distribution of spouse vs family caregivers in the sample represents a potential confound in the working vs nonworking groups. For all cohort studies, attaining a sufficient distribution of participants across all variables of potential importance is a challenge. Here, the uneven distribution precluded sufficient power to interrogate this potential interaction effectively, and must be acknowledged as a limitation. Second, measures included in this study were a selected subset, and other factors that could impact carer QoL and wellbeing may not have been included. Third, the study used EQ-5D as its primary measure of QoL. The absence of a robustly developed measure of disease-specific carer QoL has been identified by previous reviews (blinded for review ♯1, 2017; Page et al., 2017), and newly developed measures of carer QoL (SIDECAR and C-DEMQOL) hope to help address this gap (Oyebode et al., 2018; Daley et al., 2018).

Methodologically, the cross-sectional nature of the study, without latent factor and mediation analyses, precludes conclusions about causal relationships between variables. Also, using stepwise regression for the exploratory component of the analysis can lead to elevated

type I error (false positives), so future research should seek to confirm the findings. Finally, as the caregivers in this study supported persons with different dementia diagnoses, it is possible that further variations in QoL and wellbeing outcomes amongst working and non-working carers may have emerged based on diagnostic differences.

Conclusion

In conclusion, this is the first study to draw from the national data collected in the U.K. IDEAL programme to consider dementia carers based on their working status. Although progress is being made in provision of family-supportive work environments for carers (Allen, Herst, Bruck & Sutton, 2000), these improvements are not found in all organisations (APPG on Dementia, 2019), and our detailed examination of factors affecting carer wellbeing has policy implications. The regression models identified commonality in contributors to QoL and wellbeing for working and nonworking carers of PwD: namely, self-esteem and relative stress, self-efficacy, positive response to carer role, and social support. Policy makers could usefully target these psychological and social factors common across all carers to improve QoL and wellbeing. The data also identified differences. Working carers reported better QoL, as measured by the EQ-5D, and for the under 65s, better wellbeing, as measured by WHO-5, indicating the value of supporting the work role. Equally, working carers reported lower carer competence; educational input is needed here to support better skills and confidence. Finally, nonworking carers reported higher social restriction, which could be alleviated by better policies in short and longer-term respite.

References

AARP (American Association of Retired Persons) (2015) 'Caregiving in the U.S', Report, The National Alliance for Caregiving and the AARP Public Policy Institute. Available at: https://www.aarp.org/content/dam/aarp/ ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf.

Adult Social Care Statistics Team, NHS Digital (2017) Personal Social Services Survey of Adult Carers in England, 2016-17, Report. Available at: https://files.digital.nhs.uk/publication/a/o/sace_report_2016-17.pdf

Akinwande, M. O., Dikko, H. G., & Samson, A. (2015). Variance inflation factor: as a condition for the inclusion of suppressor variable (s) in regression analysis. Open Journal of Statistics, 5(07), 754.

Allen, T. D., Herst, D. E. L., Bruck, C. S. & Sutton, M. B. J. (2000). Consequences Associated With Work-to-Family Conflict: A Review and Agenda for Future Research. Journal of Occupational Health Psychology, 5(2), 278-308.

Anderson, M.D. & White, K.M. (2018). "It Has Changed My Life": An Exploration of Caregiver Experiences in Serious Illness. American Journal of Hospice & Palliative Medicine, 35(2), 266-274.

Assessments and the Care Act (2015). Available from http://www.carersuk.org/files/section/4630/factsheet-e1029--assessments-and-the-care-act-after-april-2015.pdf.

Baker, K.L. & Robertson, N. (2008). Coping with caring for someone with dementia: reviewing the literature about men. Aging and Mental Health, 12, 413–422.

Balducci, C., Mnich, E., McKee, K. J., Lamura, G., Beckmann, A., Krevers, B., Wojszel, Z. B., Nolan, M., Prouskas, C., Bien, B. & Oberg, B. (2008). Negative impact and positive value

in caregiving: validation of the COPE index in a six-country sample of carers. The Gerontologist, 48, 276-286.

Bech, P. (2004). Measuring the dimension of Psychological General Well-Being by the WHO-5. Quality of Life Newsletter. 32, 15-16.

Belle, S.H., Burgio, L., Burns, R., Coon, D., Czaja, S.J., Gallagher-Thompson, D., Gitlin, L.N., Klinger, J., Koepke, K.M., Lee, C.C., Martindale-Adams, J., Nichols, L., Schulz, R., Stahl, S., Stevens, A., Winter, L. & Zhang, S, (2006). Resources for Enhancing Alzheimer's Caregiver Health (REACH) II Investigators. Annals of Internal Medicine, 145(10), 727-38.

Braun, M., Scholz, U., Bailey, B., Perren, S., Hornung, R. & Martin, M. (2009). Dementia caregiving in spousal relationships: A dyadic perspective. Aging & mental Health, 13(2), 426 – 436.

Brickman, A.M., Riba, A., Bell, K., Marder, K., Albert, M., Brandt, J. & Stern, Y. (2002). Longitudinal assessment of patient dependence in Alzheimer disease. Archives of Neurology, 59, 1304.

Brodaty, H. & Donkin, M. (2009). Family caregivers of people with dementia. Dialogues in Clinical Neuroscience, 11(2), 217.

Bruvik, F.K., Ulstein, I.D., Ranhoff, A.H. & Engedal, A. (2012). The Quality of Life of People with Dementia and Their Family Carers. Dementia and Geriatric Cognitive Disorders, 34, 7-14.

Burckhardt, C.S. & Anderson, K.L. (2003). The Quality of Life Scale (QOLS): reliability, validity, and utilization. Health and Quality of Life Outcomes, 23, 1, 1-7.

Calasanti, T. & Bowen, M. E. (2006). Spousal caregiving and crossing gender boundaries: Maintaining gender identities. Journal of Aging Studies, 20, 253–263.

Camfield, L. & Skevington, S.M. (2008). On subjective well-being and quality of life. Journal of Health Psychology, 13(6), 764-775.

Cheng, S. (2017). Dementia Caregiver Burden: a Research Update and Critical Analysis. Current Psychiatry Reports, 19(9), 64.

Clare, L., Nelis, S.M., Quinn, C., Martyr, A., Henderson, C., Hindle, J.V., Jones, I.R., Jones, R.W., Knapp, M., Kopelman, M.D., Morris, R.G., Pickett, J.A., Rusted, J.M., Savitch, N.M., Thom, J.M., & Victor, C.R. (2014). Improving the experience of dementia and enhancing active life-living well with dementia: study protocol for the IDEAL study. Health and Quality of Life Outcomes, 12, 164.

Clare, L., Wu, Y-T., Quinn , C., Jones IR., Victor C., Nelis, S., Martyr, A., Litherland, R., Pickett J., Hindle J., Jones R., Knapp, M., Kopelman M., Morris R., Rusted J., Thom,, J., Lamont, R., Henderson, C., Rippon, I., Hillman, A., Matthews F. (2019). A comprehensive model of factors associated with capability to 'live well' for family caregivers of people living with mild-to-moderate dementia: findings from the IDEAL study. Alzheimer's Disease and Associated Disorders, 33: 29-35.

Crellin, N.E., Orrell, M., McDermott, O. & Charlesworth, G. (2014). Self-efficacy and health-related quality of life in family carers of people with dementia: a systematic review. Aging & Mental Health, 18(8), 954-969.

Daley, S., Murray, J., Farina, N., Page, T.E., Brown, A., Basset, T., Livingston, G., Bowling, A., Knapp, M. & Banerjee, S. (2018). Understanding the quality of life of family carers of people with dementia: Development of a new conceptual framework. International Journal of Geriatric Psychiatry, 1-8.

Department of Health (2009). Living well with dementia: a national dementia strategy, London: The Stationery Office.

Department of Health (2015). Department of Health, 2010 to 2015 government policy: dementia. London: The Stationery Office.

Diener, E. (2006). Guidelines for National Indicators of Subjective Well-Being and Ill-Being. Journal of Happiness Studies, 7(4), 397-404.

Doewick, A. & Southern, A. (2014). Dementia 2014: Opportunity for Change. London: Alzheimer's Society.

Dugan, A.G., Fortinsky, R.H., Barnes-Farrell, J.L., Kennt, A.M., Robison, J.T., Warren, N. & Cherniack, M.G. (2016). Associations of eldercare and completing demands with health and work outcomes among manufacturing workers. Community, Work & Family, 22, 1-19.

Ervin, K., Pallant, J. & Reid, C. (2015). Caregiver distress in dementia in rural Victoria. Australasian Journal on Ageing, 34, 235-240.

EuroQoL Group (1990). EuroQoL-a new facility for the measurement of health-related quality of life. Health Policy, 16, 199-208. Available from http://www.ncbi.nlm.nih.gov/pubmed/10109801

Farina, N., Page, T.E., Daley, S., Brown, A., Bowling, A., Basset, T., Livingston, G., Knapp, M., Murray, J. & Banerjee, S. (2017). Factors associated with the quality of life of family carers of people with dementia: a systematic review. *Alzheimer's & Dementia*, 1-10.

Fauth, E. B., Femia, E. E. & Zarit, S. H. (2015). Resistiveness to care during assistance with activities of daily living in non-institutionalized persons with dementia: associations with informal caregivers' stress and well-being. Aging & Mental Health, 1-11.

Fonareva, I. & Oken, B.S. (2014). Physiological and functional consequences of caregiving for relatives with dementia. International Psychogeriatric Association, 26(5), 725-747.

Gilliam, C.M. & Steffen, A.M. (2006). The relationship between caregiving self-efficacy and depressive symptoms in dementia family caregivers. Aging & Mental Health,10(2), 79-86.

Greene, J., Smith, R., Gardiner, M. & Timbury, G. (1982). Measuring behavioural disturbance of elderly demented patients in the community and its effects on relatives: a factor analytic study. Age and Ageing, 11, 121-126.

Häusler, A., Sánchez, A., Gellert, P., Deeken, F., Rapp, M.A. & Nordheim, J. (2016). Perceived stress and quality of life in dementia patients and their caregiving spouses: does dyadic coping matter? International Psychogeriatrics, 28(11), 1857-1866.

Healthways & Coughlin, J. (2010). Estimating the impact of caregiving and employment on well-being. Outcomes and Insight in Health Management, 2, 1-7.

Hemati Z. & Kiani D. (2016). The relationship between self-esteem and quality of life of patients with idiopathic thrombocytopenic Purpura at Isfahan's Sayed Al-Shohada Hospital, Iran, in 2013. International Journal of Haematology-Oncologiy and Stem Cell Research, 10, 79–84

Hillage, J. & Pollard, E. (1998). Research Report RR85. Department for Education and Employment.

Janssen, M. F., Pickard, A. S., Golicki, D., Gudex, C., Niewada, M., Scalone, L., Swinburn. P. & Busschbach, J. (2013). Measurement properties of the EQ-5D-5L compared to the EQ-5D-3L across eight patient groups: a multi-country study. Quality of Life Research, 22(7), 1717-1727.

Johannessen, A., Engedal, K. & Thorsen, K. (2016). Coping efforts and resilience among adult children who grew up with a parent with young-onset dementia: a qualitative follow-up study. International Journal of Qualitative Studies on Health and Well-Being, 11(10), 1-12.

Joling, K.J., Windle, G., Dröes, R., Huisman, M., Hertogh, C. M. P. M. & Woods, R.T. (2017). What are the essential features of resilience for informal caregivers of people living with dementia? A Delphi consensus examination. Aging & Mental Health, 21(5), 509-517.

Lamont, R.A., Quinn, C., Nelis, S.M., Martyr, A., Rusted, J.M., Hindle, J.V., Longdon, B., Clare, L., & on behalf of the IDEAL study team. (2019). Self-esteem, self-efficacy and optimism as psychological resources among family caregivers of people with dementia: findings from the IDEAL study. International Psychogeriatrics, 31, 1259-1266. doi: 10.1017/S1041610219001236

LaFontaine, J. & Oyebode, J.R. (2013). Family relationships and dementia: a synthesis of qualitative research including the person with dementia. Ageing & Society, 34(7), 1243-1272.

Lubben, J., Blozik, E., Gillmann, G., Iliffe, S., von Renteln Kruse, W., Beck, J.C. & Stuck, A.E. (2006). Performance of an abbreviated version of the Lubben Social Network Scale

among three European community-dwelling older adult populations. The Gerontologist, 46, 503-513.

Martyr, A., Nelis, S.M., Quinn, C., Wu, Y.-T., Lamont, R.A., Henderson, C., Clarke, R., Hindle, J.V., Thom, J.M., Jones, I.R., Morris, R.G., Rusted, J.M., Victor, C.R & Clare, L. (2018). Living well with dementia: a systematic review and correlational meta-analysis of factors associated with quality of life, well-being and life satisfaction in people with dementia. Psychological Medicine 48, 2130–2139. https://doi.org/10.1017/S0033291718000405

Masselot, A. & Caracciolo di Torella, E. (2010). Reconciling Work and Family Life in EU Law and Policy. Palgrave Macmillan.

McCabe, L., Robertson, J. & Kelly, F. (2018). Scaffolding and working together: a qualitative exploration of strategies for everyday life with dementia. Age and Ageing, 47(2), 303-310.

McKee, K.J., Philp, I., Lamura, G., Prouskas, C., Oberg, B., Krevers, B., Spazzafumo, L., Bień, B., Parker, C., Nolan, M.R., Szczerbinska, K. & COPE Partnership, C. (2003). The COPE index-a first stage assessment of negative impact, positive value and quality of support of caregiving in informal carers of older people. Aging & Mental Health, 7, 39-52.

Newbronner, L., Chamberlain, R, Borthwick, R., Baxter, M. & Glendinning, C. (2013). A road less rocky: supporting carers of people with dementia. Carers Trust.

Nicolaou, P.L., Egan, S. J., Gasson, N. & Kane, R. T. (2010). Identifying needs, burden, and distress of carers of people with Frontotemporal dementia compared to Alzheimer's disease, Dementia, 9(2), 215-235.

NurFatihah, O.A., Rahmah, M.A., Rosnah, S., Ismail., D., Khadijah, S. & ShEzat, S.P. (2013). Quality Of Life among Caregivers of Elderly With Dementia and Its Associated Factors. Journal of Nursing and Health Science, 1(2), 07-13.

Oyebode, J.R., Pini, S., Ingleson, E., Megson, M., Horton, M., Clare, L., Al-Janabi, H., Brayne, C. & Wright, P. (2018). Development of an item pool for a needs-based measure of quality of

life of carers of a family member with dementia. The Patient. 1-12. https://doi.org/10.1007/s40271-018-0334-4

Page, T. E., Farina, N., Brown, A., Daley, S., Bowling, A., Basset, T., Livingston, G., Knapp, Murray, J. & Banerjee, S. (2017). Instruments measuring the disease-specific quality of life of family carers of people with neurodegenerative diseases: a systematic review. BMJ Open, 7(3), e013611. https://doi.org/10.1136/bmjopen-2016-013611

Papastavrou, E., Tsangari, H., Karayiannis, G., Papacostas, S,. Efstathiou, G. & Sourtzi, P. (2011). Caring and coping: The dementia caregivers. Aging & Mental Health, 15(6), 702-711.

Pearlin, L. I., Mullan, J. T., Sample, S. J. & Skaff, M. M. (1990). Caregiving and the stress process: an overview of concepts and their measures. Gerontologist, 30, 583–594.

Pfau-Effinger, B., Jensen, P.H. & Flaquer, L. (2009). Formal and informal work in European societies – A comparative perspective. In Pfau-Effinger, B., Jensen, P.H. & Flaquer, L. (Eds.). Formal and Informal Work in Europe. The Hidden Work Regime, London, New York: Routledge.

Prince, M. (2004). Care arrangements for people with dementia in developing countries. International Journal of Geriatric Psychiatry, 19, 170–177.

Quinn, R., Nelis, S.M., Martyr, A., Morris, R.G., Victor, C. & Clare, L.; on behalf of the IDEAL study team(2019a). Influence of Positive and Negative Dimensions of Dementia Caregiving on Caregiver Well-Being and Satisfaction With Life: Findings From the IDEAL Study. American Journal of Geriatric Psychiatry, 27: 8; 838-848.

Quinn, R., Nelis, S.M., Martyr, A., Morris, R.G., Victor, C. & Clare, L.; on behalf of the IDEAL study team(2019b). Caregiver influences on 'living well' for people with dementia: Findings from the IDEAL study. Aging and Mental Health, DOI: 10.1080/13607863.2019.1602590

Raivio, M.M., Laakkonen, M.L. & Pitkala, K.H. (2015). Psychological well-being of spousal caregivers of persons with Alzheimer's disease and associated factors. European Geriatric Medicine, 6, 128-133.

Rattinger, G.B., Fauth, E.B., Behrens, S., Sanders, C., Schwartz, S., Norton, M.C., Corcoran, C., Mullins, C.D., Lyketsos, C.G. & Tschanz, J.T. (2016). Closer caregiver and care-recipient relationships predict lower informal costs of dementia care: The Cache County Dementia Progression Study. Dementia (London), 14(2), 220-237.

Robertson, S.M., Zarit, S.H., Duncan, L.G., Rovine, M.J. & Femia, E.E. (2007). Family caregivers' patterns of positive and negative affect. Family Relations, 56, 12-23.

Rosenberg, M. (1965). Society and the adolescent self-image. Princeton, NJ: Princeton University Press.

Russell, R. (2001). In sickness and in health: a qualitative study of elderly men who care for wives with dementia. Journal of Aging Studies, 15, 351–367.

Schalock, R.L. (2004). The concept of quality of life: what we know and do not know. Journal of Intellectual Disability Research, 48(3), 203-216.

Schölzel-Dorenbos, C.J., Draskovic, I., Vernooij-Dassen, M.J. & Olde Rikkert, M.G. (2009). Quality of life and burden of spouses of Alzheimer disease patients. Alzheimer's Disease and Associated Disorders, 23(2), 171-177.

Schrag, A., Selai, C., Jahanshahi, M. & Quinn, M.P. (2000). The EQ-5D a generic quality of life measure is a useful instrument to measure quality of life in patients with Parkinson's disease. Journal of Neurology, Neurosurgery, and Psychiatry, 69, 67-73.

Schwarzer, R. & Jerusalem, M. (1995). Generalized Self-Efficacy scale. In Weinman, J., Wright, S. & Johnston, M. Measures in health psychology: A user's portfolio. Causal and control beliefs (pp. 35-37). Windsor, UK: NFER-NELSON.

Sharma, N., Chakrabarti, S. & Grover, S. (2016). Gender differences in caregiving among family - caregivers of people with mental illnesses. World Journal of Psychiatry, 22; 6(1), 7–17.

Skevington, S.M., Lofty, M. & O'Connell, K.A. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial. A report from the WHOQOL group. Quality of Life Research, 13, 299-310.

Skevington, S.M. & Böhnke, J.R. (2018). How is Subjective well-being related to quality of life? Do we need two concepts and both measures? Social Science and Medicine, 206, 22-30.

Tarlow, B.J., Wisniewski, S.R., Belle, S.H., Rubert, M., Ory, M.G. & Gallagher-Thompson, D. (2004). Positive aspects of caregiving, contributions of the REACH project to the development of a new measure for Alzheimer's caregiving. Research on Aging, 26, 429–453.

Tyack, C. & Camic, P. M. (2017). Touchscreen interventions and the well-being of people with dementia and caregivers: A systematic review. International Psychogeriatrics, 29, 1261–1280.

Utz, R.L., Lund, D.A., Caserta, M.S. & Wright, S.D. (2011). The Benefits of Respite Time-Use: A Comparison of Employed and Nonemployed Caregivers. Journal of Applied Gerontology, 31(3), 438-461.

Wang, Y., Shyu, Y. L., Tsai, W., Yang, P. & Yao, G. (2013). Exploring conflict between caregiving and work for caregivers of elders with dementia: a cross‐sectional, correlational study. Journal of Advanced Nursing, 69(5), 1051-1062

Full Cohort	Working status	N	Mean	Std. Dev	t	df	Sig. (2-tailed)	Age-matched subsample	Working status	N	Mean	Std. Dev	t	df	Sig. (2-tailed)
Age at baseline	Working	215	55.55	9.25	-24.79	1185	0.001	Age at baseline	Working	184	52.92	6.88	-7.94	360	0.001
	Non-working	972	72.36	8.94					Non-working	178	58.54	6.58			
Female %	Working	79.1						Female %	Working	81.5					
	Non-working	66.5							Non-working	79.2					
Spouse %	Working	38.1						Spouse %	Working	27.7					
	Non-working	89.6							Non-working	60.7					
EQ-5D-3L Index	Working	214	0.88	0.16	6.32	1160	0.001	EQ-5D-3L Index	Working	184	0.88	0.17	5.29	359	0.001
	Non-working	948	0.78	0.21					Non-working	177	0.75	0.28			
WHO5	Working	208	14.16	4.6	0.88	1152	0.381	WHO5	Working	179	14.06	4.55	2.12	351	0.034
	Non-working	946	13.83	4.96					Non-working	174	12.97	5.08			
SELF-ESTEEM	Working	205	21.42	4.67	0.81	1129	0.417	SELF-ESTEEM	Working	176	21.21	4.58	2.6	345	0.01
(REVERSED)	Non-working	926	21.14	4.48				(REVERSED)	Non-working	171	19.86	5.1			
RELATIVE STRESS	Working	200	18.39	9.48	-0.95	1109	0.342	RELATIVE STRESS	Working	171	18.24	9.58	-2.69	341	0.008
	Non-working	911	19.11	9.74					Non-working	172	21.16	10.53			
DEPENDENCE	Working	198	5.66	2.5	0.07	1113	0.94	DEPENDENCE	Working	172	5.73	2.47	-1.4	339	0.163
	Non-working	917	5.64	2.63					Non-working	169	6.11	2.47			
SELF EFFICACY	Working	206	32.58	4.2	3.63	1136	0.001	SELF EFFICACY	Working	178	32.46	4.23	3.05	350	0.002
	Non-working	932	31.38	4.28					Non-working	174	31.06	4.39			
MANAGEMENT OF	Working	207	9.84	1.94	1.41	1138	0.16	MANAGEMENT OF	Working	178	9.77	1.96	-0.15	351	0.881
SITUATION	Non-working	933	9.62	2.01				SITUATION	Non-working	175	9.81	1.85			
ROLE CAPTIVITY	Working	206	5.46	2.07	-0.2	1140	0.838	ROLE CAPTIVITY	Working	177	5.41	2.034	-3.16	349	0.002
	Non-working	936	5.49	2.26					Non-working	174	6.19	2.54			
POSITIVE CAREGIVING	Working	206	28.61	7.04	0.55	1141	0.582	POSITIVE CAREGIVING	Working	177	28.81	6.69	2.65	349	0.008
	Non-working	937	28.3	7.41					Non-working	174	26.8	7.52			
CAREGIVING	Working	208	8.96	1.6	-1.99	1144	0.046	CAREGIVING	Working	179	8.9	1.55	-0.77	352	0.441
COMPETENCE	Non-working	938	9.21	1.67				COMPETENCE	Non-working	175	9.03	1.73			
MODIFIED SOCIAL	Working	208	3.32	1.32	-1.94	1141	0.053	MODIFIED SOCIAL	Working	179	3.29	1.34	-1.73	351	0.085

RESTRICTION	Non-working	935	3.52	1.35				RESTRICTION	Non-working	174	3.54	1.38			
WHO QOL SOCIAL	Working	207	7.93	1.49	-0.26	1151	0.793	WHO QOL SOCIAL	Working	178	7.95	1.51	1.58	350	0.115
RELATIONSHIPS	Non-working	946	7.96	1.37				RELATIONSHIPS	Non-working	174	7.69	1.57			
LUBBEN social network	Working	206	17.67	5.42	0.33	1141	0.744	LUBBEN social network	Working	176	17.78	5.48	1.94	349	0.053
	Non-working	937	17.53	5.63					Non-working	175	16.61	5.86			

Table 1: Descriptive data for the full and the age-matched samples, stratified by working status.

Table 2 Model A: First two steps and final model (full model in Appendix 2). Dependent variable EQ-5D

2a. full sample

	Unstandardized B	Standardized Beta	Sig.	Adjusted R	Delta r	F	P
Step 1				0.047		12.98	0.001
Age of carer	2.342E-5	.001	.977				
Gender: Male	-.044	-.098	.002				
Carer-Dyad reln	.104	.022	.000				
Dependence	-.008	-.103	.001				
Step 2				0.065	.018	14.51	0.001
Age of carer	.002	.083	.068				
Gender: Male	-.042	-.094	.003				
Carer-Dyad reln	.085	.161	.000				
Dependence	-.008	-.092	.003				
Working status	-.094	-.174	.000				
Step 5. Final model				0.184	.012	28.43	0.001
Age of carer	.001	.043	.323				
Gender: Male	-.019	-.041	.173				
Carer-Dyad reln	.060	.114	.004				
Dependence	.001	.017	.609				
Working status	-.081	-.151	.000				
Self-Esteem	.012	.251	.000				
Relative Stress	-.006	-.270	.000				
Role Captivity	.015	.156	.000				

2b. age-matched sample

		Unstandardized B	Standardized Beta	Sig.	Adjusted R	Delta r	F	P
Step 1					.054		5.47	0.001
	Age of carer	.000	.011	.860				
	Gender	-.035	-.061	.269				
	Carer-Dyad reln	.115	.246	.000				
	Dependence	-.010	-.107	.056				
Step 2					.100	.046	7.90	0.001
	Age of carer	.003	.105	.114				
	Gender	-.037	-.065	.230				
	Carer-Dyad reln	.098	.210	.001				
	Dependence	-.007	-.074	.176				
	Working status	-.115	-.249	.000				
Step 5.	Final model				.256	.011	14.38	0.001
	Age of carer	.000	.006	.919				
	Gender	-.015	-.026	.591				
	Carer-Dyad reln	.052	.112	.064				
	Dependence	.007	.076	.187				
	Working status	-.081	-.174	.002				
	Self Esteem	.014	.282	.000				
	Relative Stress	-.008	-.351	.000				
	Role Captivity	.017	.171	.020				

Table 3 Model B: First two steps and final model (full model in Appendix 3). Dependent variable WHO-5

3a: full sample

	Unstandardized B	Standardized Beta	Sig	Adjusted R	Delta r	F	P
Step 1				.071		6.965	0.001
Age of carer	.099	.146	.022				
Gender	-1.242	-.103	.062				
Carer-Dyad reln	2.165	.223	.001				
Dependence	-.400	-.204	-.000				
Step 2				.082	0.011	6.51	0.001
Age of carer	.131	.194	.004				
Gender	-1.256	-.104	.057				
Carer-Dyad reln	1.976	.204	.002				
Dependence	-.369	-.188	.001				
Working status	-1.247	-.129	.037				
Step 9 Final model				.471	.003	74.36	0.001
Age of carer	.003	.008	.828				
Gender	-.972	-.093	.000				
Carer-Dyad reln	.592	.048	.124				
Dependence	-.053	-.028	.294				
Working status	.076	.006	.838				
Relative Stress	-.176	-.353	.000				
Self Esteem	.243	.227	.000				
WHO-QOL social Relationships	.600	.175	.000				
Self Efficacy	.101	.089	.001				
Lubben Social network	.073	.084	.001				

3b. age-matched sample

		Unstandardized B	Standardized Beta	Sig	Adjusted R	Delta r	F	P
Step 1					.071		6.965	0.001
	Age of carer	.099	.146	.022				
	Gender	-1.242	-.103	.062				
	Carer-Dyad reln	2.165	.223	.001				
	Dependence	-.400	-.204	-.000				
Step 2					.082	0.011	6.51	0.001
	Age of carer	.131	.194	.004				
	Gender	-1.256	-.104	.057				
	Carer-Dyad reln	1.976	.204	.002				
	Dependence	-.369	-.188	.001				
	Working status	-1.247	-.129	.037				
Step 6	Final model				.470	010	31.54	0.001
	Age of carer	.062	.091	077				
	Gender	-.709	-.059	.162				
	Carer-Dyad reln	.869	.090	070				
	Dependence	-.007	-.004	.938				
	Working status	-.079	-.008	.865				
	Self Esteem	.305	.304	.000				
	Relative Stress	-.128	-.268	.000				
	WHO-QOL social Relationships	.647	.208	.000				
	Self Efficacy	.146	.126	.010				